

Kentucky Services For Children And Youth

**Directory of Services
For Children and Youth with Special Health Care, Educational, and Vocational
Rehabilitation Needs**

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KY Commission for Children with
Special Health Care Needs
982 Eastern Parkway
Louisville KY 40217
(502) 595-4459
(800) 232-1160**

YOUR CONCERNS AND WHO TO CALL

Financial assistance only---Programs which may provide financial aid.

Supplemental Security Income (SSI)---Provides basic income for needy children under 18 who are blind or have a severe disability or chronic illness. In Kentucky, children eligible for SSI will also receive a Medical Card. Contact the local Social Security Administration office in your area. Look in telephone blue government pages or check the excellent website: http://www.ssa.gov/SSA_Home.html and click on the link for Disability and SSI

Medicaid Services---four possibilities to explore:

- ≈ Family qualifies for medical assistance based on family income.
- ≈ The "Spend Down" program may apply when families have income above the regular Medicaid standard. They can spend down income by presenting bills for medical services roughly equal to their income for a month or quarter.
- ≈ The Medicaid Disabled Child Calculation which allows a child who is disabled and living in the home with their parents a more liberal eligibility determination.
- ≈ The Home and Community Based Waiver Program (HCB). This special Medicaid program pays home health agencies for a number of services that are not usually covered by Medicaid, but that allows a child or young person who meets the level of care for a nursing facility to remain at home. Examples of services include assessment of needs, case-management, minor home adaptations, and respite. A special income level is used in determining financial eligibility for those individuals who meet the level of care determination, but who are not already Medicaid recipients. The only income to be considered for this program is that of the person needing services. HCB Waiver Services must be ordered by a physician and provided by a home health agency participating in the program.

Application under these Medicaid eligibility standards may be made at the Cabinet for Families and Children/ Department for Community Based Services/Medicaid Office in your county of residence, or check the state Medicaid website: <http://chs.state.ky.us/dms/default.htm> DCBS/Medicaid staff can also tell you what medical services are covered. Medical providers who take the Medicaid Card also should know which of their services are covered.

CHILD RECEIVES A MEDICAL CARD BUT HAS EXTRAORDINARY MEDICAL NEEDS NOT COVERED BY REGULAR MEDICAID PROGRAM

EPSDT

- ≈ Contact Medicaid Services for determination of Medicaid coverage. Federal law mandates that states pay for services that are medically necessary but not otherwise included in the state Medicaid plan. These special services may be accessed through the EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT (EPSDT) PROGRAM. However, all covered services, whether in the state Medicaid plan or not must be listed in Section 1905 (a) of the Social Security Act. All services must be

medically necessary and pre-authorized. Call the state EPSDT coordinator in Frankfort at the state Dept. for Medicaid Services (502) 564-6890.

Services and Financial Aid---Programs that provide services at no charge or at minimal cost to families (charges may be on a sliding fee scale based on family income and ability to pay).

SEVERE AND CHRONIC ILLNESS, GENETIC DISORDERS, PHYSICAL DISABILITIES, SPEECH AND HEARING IMPAIRMENTS, BLINDNESS ---For children with speech and/or hearing impairments, serious chronic illnesses such as Cystic Fibrosis, birth defects which require ongoing treatment and surgeries (e.g., Spina Bifida), or children who have been injured in an accident and need extensive surgeries and medical care.

You may want to begin by consulting your child's pediatrician or family doctor. If your child is a newborn, contact the social worker at the hospital where your child was born. Other resources that may include actual medical care as well as help with the costs of treatment include:

- ≈ **The Commission for Children with Special Health Care Needs (CCSHCN)**---(ages 0-21) Offers diagnostic, rehabilitative, medical case management and medical treatment services for a number of chronic illnesses and physical disabilities. Call 1-800-232-1160.
- ≈ **Local Health Departments**---(Children's Health Services for ages 0-21) Offer a wide variety of maternal and child health services and family services including pre-natal care, family planning, well-child checkups, immunizations, nutrition services, genetic and developmental evaluation services and home health services. (Not all services are available in every health department.) Call your local health department for information.
- ≈ **Shriners Hospitals for Crippled Children**---(ages 0-18) Offers comprehensive inpatient and outpatient treatment of orthopedic problems, burns, and other selected health care problems. Located at 1900 Richmond Road, Lexington, KY 40502---(606)266-2101.
- ≈ **The Commission on the Deaf and Hard of Hearing**---(Serves children and adults who are deaf or hard of hearing.) Acts as an advocate for deaf and hard of hearing persons on legislative issues as well as a consultant to the Governor, General Assembly and various state and local governmental agencies concerning policies and programs that pertain to people with hearing loss. Also provides information and referral services. A TTY Distribution Program is provided for eligible persons.---1-800-372-2907 (V/TDD)
- ≈ **The Kentucky School for the Deaf: Early Childhood Program**---(ages 0-6) Offers family education and preschool services for children who are deaf or hard-of hearing. Call (606) 239-7017 (V/TDD).
- ≈ **KY Easter Seals Society** Services for speech and hearing impairments. Check your local phone book white business pages listing for Easter Seals or yellow pages under speech.

- ≈ **Hospice**---For children and families who are coping with a child's terminal illness, this program provides skilled nursing, social work services, counseling, and assistance in acquiring medical equipment, supplies, medications and other professional services required by a plan of care. This program is not available statewide. Call the Coordinator for Children's Services---(800)264-0521 or (502) 456-6200 at Hospice of Louisville for information regarding availability of services in your area.
- ≈ **Visually Impaired Preschool Services**---(ages birth through preschool) Statewide outreach services providing information, support and referral to local agencies to parents of visually impaired preschool-aged children. Call (502) 636-3207
- ≈ **The Kentucky School for the Blind**---(ages preschool through grade 12) Offers assessment, counseling, and referral for preschool age children and both short and long term residential school programs for school age children. Call (502) 897-1583.
- ≈ **The Kentucky Assistive Technology Services Network (KATS)**---makes assistive technologies (computer-based equipment, mechanical, electronic, non-mechanical or non-electric aid, or specialized instructional materials) and their related services more accessible to all Kentuckians with disabilities. KATS Network Coordinating Center-- 1-800-327-5287.
 - Website: <http://www.katsnet.org>

REGIONAL CENTERS:

Northern KY
Contact: Deborah Dacey
Redwood Rehabilitation Center
71 Orphanage Rd.
Ft. Mitchell KY 41017
(606) 331-0880

BLUEGRASS TECHNOLOGY CENTER
169 North Limestone Street
Lexington KY 40507
(606) 255-9951 or (800) 209-7767

enTECH
Enabling Technologies of Kentuckiana
LFPL~301 York Street~Louisville KY 40203
(502) 574-1673 or (800) 890-1840

WESTERN KY ASSISTIVE TECHNOLOGY CONSORTIUM, INC.
607 Poplar Street, Suite 207
P O Box 266 ~Murray KY 42071
(502)759-4233 or (800) 209-6202

DEVELOPMENTAL DELAYS: Early Childhood (Birth to Four)

- ≈ **First Steps**, Kentucky Early Intervention System--- (ages 0-3) For families who are concerned that their child is not learning or growing at the same rate as other children the same age, First Steps provides an array of services for infants and toddlers who have or are at risk for developmental delays. Call 1-800-442-0087 (V/TDD: 502/ 564-4448. Website: <http://commissionkids.state.ky.us/firststeps/default.htm>
- ≈ **Head Start**---Provides comprehensive child development services to three and four year old children for income eligible families. Head Start encourages family and community support for programs focusing on Education, Health, Social Services, and Parent Involvement. Additionally, ten percent of Head Start's enrollment is reserved for children professionally diagnosed as disabled. These children and their families receive a range of developmental services including collaboration with appropriate community agencies and the local school district to meet the special needs of the child with disabilities. To locate the Head Start program nearest you, check this website: <http://www.acf.hhs.gov/programs/hsb/hsweb/index.jsp> or contact the KY Head Start Collaboration Director Earl Trevor at: (502) 564-8099 or by email at: earlr.trevor@mail.state.ky.us

CHILDREN WITH LEARNING DISABILITIES IN NEED OF SPECIAL EDUCATION SERVICES

- ≈ **Local Public Schools**--Under the Individuals with Disabilities Education Act (IDEA)* local public school districts are responsible for providing a free, appropriate public education to children with educational disabilities. Services are available for identified children beginning at age 3 and continuing to age 21. Call the Director of Special Education at your local school board or call the state Dept. of Education at 1-800-533-5372.
 - *If you are unsure about your child's rights to educational services or you need help with talking to school personnel, contact the KY Special Parent Involvement Network (SPIN) at 1-800-525-SPIN. You will receive information from the state office as well as be referred to a local SPIN representative.
- ≈ **Regional Mental Health/Mental Retardation and Developmental Disabilities Programs (Comprehensive Care Centers)**--- Provide evaluations, counseling and referral services. Check your local phone book white business pages under Mental Health or yellow pages under Mental Retardation and Developmentally Disabled Services.
- ≈ **Protection and Advocacy Division**---Protects and advocates human and legal rights of Kentuckians with developmental disabilities or mental illnesses. Call 1-800-372-2988 or (502) 564-2967.
- ≈ **U of K Human Development Institute**, Assessment and Consultation Program-- Provides comprehensive diagnostic evaluations and treatment or program recommendations. Call (606) 257-1254.

- ≈ **U of L Child Evaluation Center**---Provides comprehensive diagnostic evaluations, treatment recommendations, and some therapy and counseling services. Call (502) 852-5331.

TRANSITION AND VOCATIONAL CONCERNS----Your child is aging out of one program and needs ongoing assistance and referral information.

- ≈ --All school age children receiving special education services must have an Individual Education Program (IEP) reviewed and revised on at least an annual basis. Consult your child's teacher, school counselor, principal, or district Director of Special Education about your child's education needs.
- ≈ High School students receiving Special Education services may receive education services to age 21. In addition to services provided through the school system, other programs that can help with transition needs of older adolescents and young adults are the community-based comprehensive care centers and the **Dept. for Vocational Rehabilitation. To find out about Vocational Rehabilitation call 1-800-372-7172 (Voice or TTD).**

OBTAINING AND MAINTAINING YOUR CHILD'S MEDICAL AND EDUCATIONAL RECORDS

ESTABLISHING A PERSONAL FILE SYSTEM---One of the most important things you need to do as the parent of a child with serious medical problems or with special education needs is to keep and maintain copies of your child's medical and/or educational records.

----You will need to take past information with you to new health care providers and if you go to apply for any type of medical or financial assistance.

----When you apply for SSI it will speed the application process if you have copies of your child's medical records to turn in with the application. The Social Security Office will advise you on the medical information necessary to file a claim.

----Keep this information together along with a calendar of appointments, a history of any tests, when and where your child received medical treatment, information about prescriptions and any allergic reactions.

----Use a zippered notebook with pockets and file folders to carry information with you to appointments. (Always keep an extra copy of your child's social security card and birth certificate in this notebook.)

----Keep copies of things you may need in a cardboard file box, cabinet, or drawer that you have reserved just for this purpose.

HOW TO OBTAIN MEDICAL RECORDS—you are entitled to one free copy of your medical records

≈ Kentucky House Bill 250*, enacted 4/15/94, requires health care providers to provide to a patient, at the patient's request, a copy of the patient's medical record at no charge to the patient. It also permits a fee of up to \$1.00 per page for second or subsequent copies.

(* Note that this state bill does not apply to medical reports purchased by the federally funded Disability Determinations Services.)

HOW TO OBTAIN EDUCATIONAL RECORDS

Your rights regarding records are spelled out in FERPA (Federal Educational Rights and Privacy Act). You have the right to review your child's records from school.

---The school must let you review the file.

---They don't have to give you copies unless that is the only reasonable way for you to review the file.

---Most places will make copies if you ask.

---They can charge you a reasonable fee for copying.

----Make sure what should be there, is there. Look for evaluations, plans, measures of progress.

---If you have supplied information from other sources, it should be there.

---Check for Accuracy

---If you disagree with anything, you may ask to have the records corrected. If the school refuses, they have to let you add a letter of correction to the file.

---If there is sensitive information regarding other family members (as might be in a psychiatric record), you can have it removed.

*If there is a disagreement about removing it, there are provisions for a "hearing" in FERPA.

QUICK REFERENCE TO KENTUCKY RESOURCES FOR CHILDREN WITH SPECIAL HEALTH, EDUCATIONAL, AND VOCATIONAL REHABILITATION NEEDS

First Steps---1-800-442-0087 (V/TDD: (502) 564-4448) or website:

<http://chs.ky.gov/commissionkids/firststeps/default.htm>

Head Start---1-502-564-8099 or website: <http://www.acf.hhs.gov/programs/hsb/hsweb/index.jsp>

The Commission for Children with Special Health Care Needs (CCSHCN)---
1-800-232-1160 or website: <http://chs.ky.gov/commissionkids>

Shriners Hospitals for Crippled Children---(606)266-2101

Hospice of Louisville---Contact Coordinator for Children's Services---(800)264-0521 or (502) 456-6200

The Commission on the Deaf and Hard of Hearing---1-800-372-2907 (V/TTY)

The Kentucky School for the Deaf: Early Childhood Program---(606) 239-7017
(V/TDD)

KY Easter Seals Society---Check your local phone book white business pages under Easter Seals or yellow pages under speech.

The Kentucky School for the Blind---(502) 897-1583

Visually Impaired Preschool Services---(502) 636-3207

KY Dept. of Education Information Line---1-800-533-5372

U of K Human Development Institute, Maternal and Child Health Program---
(606) 257-1254

U of L Child Evaluation Center---(502) 852-5331

Division of Protection and Advocacy---1-800-372-2988

KY Assistive Technology Service (KATS) Network---1-800-327-5287

CHECK YOUR LOCAL TELEPHONE LISTING (Blue Government Pages or White Business Pages) FOR THE FOLLOWING:

Social Security Administration---Supplemental Security Income (SSI)_____

Dept. Community Based Services (Medical Card, Food Stamps, AFDC)
(Child Protective Services, Emergency Family Assistance _____)

Local Health Department_____

Local Commission for Children with Special Health Care Needs---_____

Regional Comprehensive Care Center/Local office---_____

Head Start_____

FAMILY SUPPORT GROUPS

Talking with other families of children with disabilities is one of the best ways to find support. Other parents who have already been working with various programs in the health care and educational systems are willing to share their knowledge and experiences with you. Families who have been able to cope with their own special needs children will understand your concerns and give you encouragement to meet your child's needs. Some groups to contact are:

PiNK Family Network & Family Voices of KY
Veronica Wright Brown
P. O. Box 99367
Louisville, KY 40269-0367
(502) 479-7465
(502) 267-2455 fax
web page: KYP2P.org

Autism Society of KY---(502) 454-6787

Kentucky Disabilities Coalition---(502) 875-1871
or 1-800-977-7505

KY-SPIN (Special Parent Involvement Network)--1-800-525-7746

The Spina Bifida Association of KY---(502) 637-7363

Council on Mental Retardation: Parent Outreach Program---Offers support and information for families of children and adults with disabilities that include mental retardation. Serves Jefferson County, the counties surrounding it and Southern Indiana. (502) 584-1239 or website:
www.councilonmr.org

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